



STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. Box 3378
Honolulu, HI 96801-3378

In reply, please refer to:
File:

NEUROTRAUMA ADVISORY BOARD (NTAB)

MEETING MINUTES

June 23, 2017

Present: Rita Manriquez, Scott Sagum, Molly Tribey, Stella Wong, Lyna Burien, Angie Enoka

Excused: Milton Takara, Valerie Yamada

Others: Violet Horvath, Director, Pacific Disabilities Center, HNTR; Cora Speck, Queen's Medical Center; Tina Robertson, Queen's Medical Center Tele-stroke; Howard Lesser, Hawaii Disabilities Rights Center; Rein Terrado, Hawaii Disabilities Rights Center

DOH Staff: Curtis Inouye, Neurotrauma Supports; Chelsea Ko, Neurotrauma Supports; Cristina Valenzuela, Neurotrauma Supports

I. Call to Order – Meeting was called to order at 2:00pm by Chair Scott Sagum. Quorum present.

II. Approval of Minutes from the April 28, 2017 meeting –

Correction to the Neighbor Island TBI Activity section:

Brochures were given to the Mayor's Advisory Committee for Equal Access (MACEA) for people with disabilities not the American Disabilities Association

Stella Wong made a motion to accept the minutes as modified. Board Member Molly Tribey seconded that motion. All Board Members present voted in favor of minutes being accepted as written. No questions or discussions.

III. Review of Agenda – All Board Members present voted in favor of accepting the agenda. No questions or discussions.

IV. New Business

NEUROTRAUMA ADVISORY BOARD (NTAB)

MEETING MINUTES

June 23, 2017

Page 1

A. Hawaii Neurotrauma Registry Survey Questions:

The Hawaii Neurotrauma Registry Survey was designed to identify the needs of individuals who have had a traumatic brain injury, stroke, and/or spinal cord injury. It currently consists of 52 questions that asks for the individual's contact information, demographics, and injury information. However, due to its lengthy format and application time, a shorter version was created to display just 27 registry questions.

Per DOH Staff Chelsea Ko, the shorter questionnaire also re-focuses on what the individual needs are, what services they have tried but did not meet their need, and identify service gaps. The draft was presented to the Board for review.

Topic suggestion/discussions:

- *Having an option to opt out of having to provide contact information*
- *Using an alternative word for "registry"*

B. Spinal Cord Injury Awareness Month (September 2017):

- *The Hawaiian Lifeguard Association will be hosting a conference; agenda will cover ocean safety, including prevention of spinal cord injury and surfer's myelopathy*
- *Cora Speck of Queen's Medical Center suggested an inquiry with Access Surf for possible volunteer opportunities. Access Surf is a non-profit organization that offers a variety of water-based programs for people with disabilities*
- *Neurotrauma Supports will be meeting with the Hawaiian Lifeguard Association and Emergency Medical Services and Injury Prevention Branch to discuss the possibility of future coordinated efforts*

*V. **Old Business***

A. Pacific Disabilities Center (PDC)/Hawaii Neurotrauma Registry (HNTR) Update:

(From the HNTR Report distributed during the last meeting, as reported by Violet Horvath)

Contract Status-

- *The previous contract ended May 19, 2017. The extension to the contract for the period of May 20-December 19, 2017 was signed by Governor Ige on June 15, 2017.*

Registry Participation-

- *There are 203 unique individuals in the registry; three people surveyed in May and three in June 2017*
- *HNTR is now tracking the amount of people to whom information and referral services were provided*

Plan for increasing number of presentations-

- *Staff is currently working on contacting people/organizations regarding presentations*

Changes to HNTR survey-

- *Questions for second and third neurotrauma injury removed; replaced with a question that asks if person had more than one injury. If yes, Project Coordinator will contact and ask questions about all other neurotrauma injuries*
- *Additional changes to survey and procedures as noted in the New Business of meeting agenda*

Link to HNTR Survey is now on the Neurotrauma Supports website-

- <http://health.hawaii.gov/nt/>

HNTR e-newsletter

- *Issue 6 launched on May 10 for Stroke Awareness Month*
- *Issue 7 is scheduled for July 2017 with a focus on spinal cord injuries*

B. Hawaiian Islands Regional Stroke (HIRS) Network Update:

(From the HIRS Report distributed during the last meeting, as reported by Tina Robertson)

There are currently eight active tele-stroke sites; Molokai General Hospital, Wahiawa General Hospital, Hilo Medical Center, The Queen's Medical Center-West O'ahu, Kona Community Hospital, Maui Memorial Medical Center, North Hawaii Community Hospital, and The Queen's Medical Center-Punchbowl. Doctors, nurses, hospitalists, and the administration have been educated on stroke care paths and protocols and in-serviced on use of the technology.

Kabuku Hospital will be the next hospital added to the network. The contract is fully executed, the tele-stroke equipment has been installed, and the credentialing process is underway.

Other important highlights:

- *177 tPA administrations; 33 tPA for the activity year (1/1/17-6/9/17)*
- *Two new neurohospitalists will be joining the tele-stroke team*
- *A medical student will be gathering data on tPA rates and outcomes on the first group of patients; report will be shared at a later time*

C. Brain Injury Association of Hawaii Update:

No new update

D. Neighbor Island TBI Activities Update:

No new update

E. DOH Update:

1. Neurotrauma Supports Strategic Plan:

The Neurotrauma Supports Strategic Plan has been approved and signed by the DOH Director; it is posted on the Neurotrauma website.

Neurotrauma Supports plans to form a committee to address goals and objectives

2. Neurotrauma Brochure:

The Neurotrauma brochure has been edited to reflect feedback and suggestions; it is currently being reviewed by the State Communications office

3. *NTAB Board Members:*

Due to the resignation of several board members, NTAB is actively looking to fill three positions: two people from the private sector and one from a trauma center.

VI. *Announcements*

Brain Injury Association of Hawaii

Support Group and Educational Meetings

1. *First Saturdays, 1:00-3:00 p.m., Rehabilitation Hospital of the Pacific, Conference Room #4.*
2. *2nd and 3rd Wednesdays, 6:00-8:00 p.m., Rehabilitation Hospital of the Pacific, Wo Conference Room #4*

VII. *Next Meeting:*

Date: August 25, 2017

Location: Kalanimoku VCC and Neighbor Island Sites

Time: 1:30 p.m. to 4:00 p.m.

Meeting Adjourned at 3:25 p.m.



The colorful masks displayed at Cardinal Hill Rehabilitation Hospital in Lexington, Kentucky, are as different as the people who designed them. However, they all have one thing in common – they were created by brain injury survivors.

The traveling exhibit in Kentucky was on display at Cardinal Hill this fall and is part of the national project, Unmasking Brain Injury. Started at Hinds' Feet Farm in North Carolina, a special home for brain injury survivors, Unmasking Brain Injury began as a way for survivors to express themselves. They are given a blank cardboard mask and an array of art supplies to decorate it. The completed work includes a brief description, explaining the meaning behind the mask. For one brain injury survivor, the color yellow on her mask represents the seizures she has at night, and copper is used to describe "the sadness I feel when this happens." Another swirls grays and whites to show the grief of losing his old self along with the "acceptance of the new me." "It's really incredibly moving," said Michelle Graybeal, director of case management at Cardinal Hill. "If you read all the descriptions ... It's such a unique way to look at how it's affecting them."

The Kentucky display has 32 masks created by brain injury survivors from all over the state, including some Cardinal Hill patients. Michelle, a board member of the Brain Injury Alliance of Kentucky, said in addition to serving as a creative outlet for these survivors, it's also helping educate the community on the prevalence of brain injury, as well as the impact it has on its survivors, added Tonia Wells. Tonia is the brain injury program director for the Kentucky Department of Aging and Independent Living. She heard about Unmasking Brain Injury at a national convention earlier this year.

UNMASKED

A NATIONAL PROJECT IS HELPING BRAIN INJURY SURVIVORS EXPRESS WHAT IT'S LIKE TO LIVE WITH THEIR CONDITION.

B “Brain injury really is a huge epidemic in our society,” Tonia said. “It’s a silent epidemic, and that’s where we hope this can help.”

Being a former case manager at Cardinal Hill, Tonia said it was one of the first hospitals she contacted about participating. Michelle along with Monica Davis, the therapy team leader for the inpatient brain injury and stroke units at the hospital, quickly agreed. The state’s brain injury program provided the masks, and the hospital provided the art supplies. “We probably turned in about eight to 10 masks,” Monica said. “The physical therapists, speech and occupational therapists were all involved. We went to the gym, and they painted, and we talked about the masks. Some had a little anger, and some felt their bodies were different now. This was just a good way to express those emotions and feelings. The patients loved it.”

So have the many who have viewed the masks since Hinds’ Feet Farm started the project last year. Now more than 20 states are participating in Unmasking Brain Injury, with a website displaying the many masks and their stories and several traveling exhibits, such as the one in Kentucky. After its display at Cardinal Hill, the exhibit is headed to a hospital in Louisville. Michelle said Unmasking Brain Injury is also being used to help lobby for legislation to prevent brain injuries, such as a bike helmet law now under consideration in Kentucky, as well as funding for brain injury survivor programs. She also hopes the colorful masks and stories behind them will spread awareness to this all-too common condition and the impact it has on its survivors. “This is giving people, not just politicians, an idea of how many survivors there are out there,” she said. “There may be one sitting next to you, and you wouldn’t know it. A lot suffer in silence. The thing that really strikes me is that these really get to the heart of who that person is.”

Tears – Represents all the crying I have done and my loss of emotional control since my injury.
Frown – My sadness and not understanding.

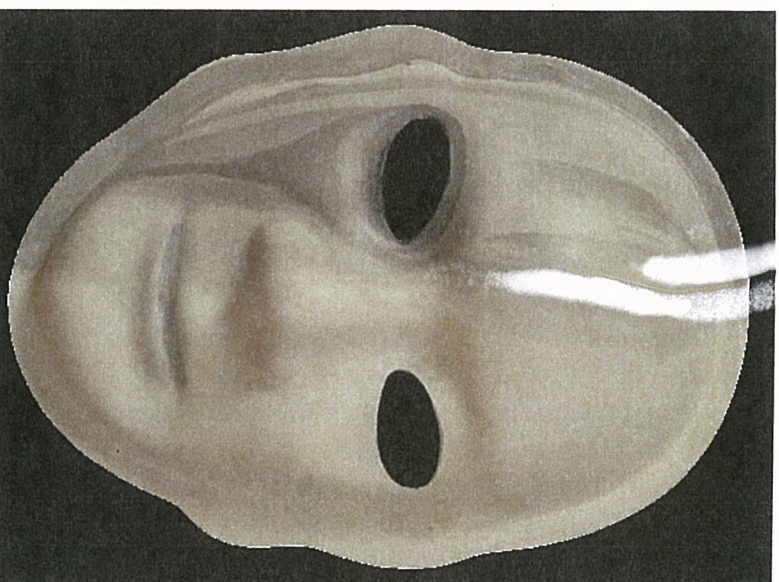


standing strong

Name: Steven

Brain Injury: Motor vehicle accident

Explanation of Mask: The mask I made to explain what I feel like. I'm not the only one in the world who has a brain injury. There are a lot of people in the world who have the same brain injury. I don't get down and I'll always think positive. Nothing will ever get me down.



a second chance

Name: Mark

Brain Injury: Motor vehicle accident

Explanation of Mask: Grief from loss of ones-self. Acceptance of the new me. Easy words to say but very difficult and painful. Finding the new me I found to be a surprising discovery re-inventing myself. Like this mask very dark and gray world of pain and confusion to a clean blank canvas; my second chance. Art has helped me heal talents uncovered. *A life renewed.*

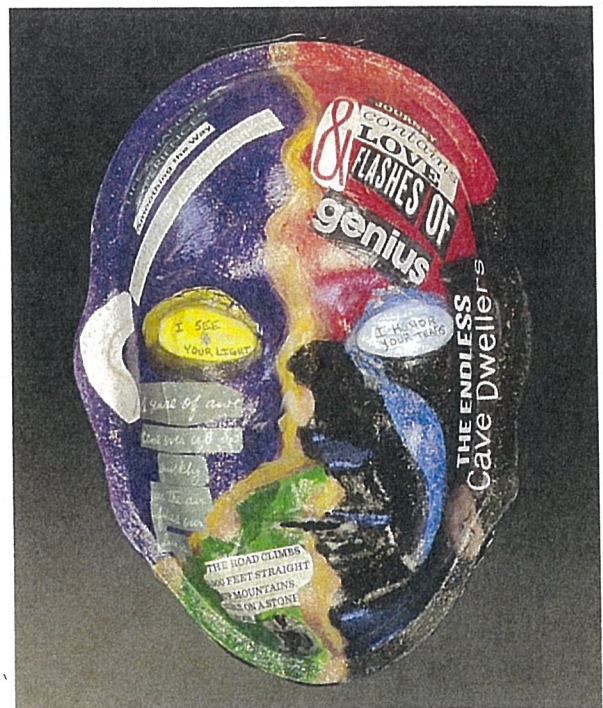


Name: **Mary A.**

City: **Albuquerque**

Brain Injury: A truck driven by a person on a cell phone hit my small car and threw it into the truck ahead of me – so I was hit twice.

Explanation of Mask: I wanted to be a whole person when I grew up (matured). Someone uncaring took all my hard work of becoming “my beautiful me.” I am damaged inside and it’s dark in there now. Only a few rays of essence still give radiance to my life now. I am so ashamed of my disability and my PTSD effects. I wish I could tell my legs to work right again. I am scared about the eventual path of my life because I do not want to be scared. I try to be serene and peaceful by remembering the radiance and the sparkle that remains. I try to build on that. Seems silly at my age, but I am stubbornly resilient. They should have empathy training for the people that injure other people with reckless driving.



Name: **Tiffany**

City: **Albuquerque**

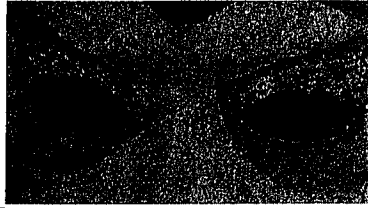
Brain Injury: Acquired Brain Injury from Cerebral Palsy

Explanation of Mask: I call the mask “the Paradox.” It is representative of all the different aspects of my journey as a person with a brain injury. The black portion with the tear is representative of the pain, anger, resentment, fear, and sense of aloneness and sadness. The green portion represents the growth and healing along the way. The purple represents empathy, compassion, and courage that I experienced and witness in others and the light that brings. The red portion represents the passion and the sense of feeling expanded through living with a brain injury, and the boldness and bravery and immense love that goes along with it. The lighting bolt in the middle represents the way the world provides a space for one’s light to shine through. The opening in the mouth depicts all these aspects coming together to help me use my voice to empower others on their journey. “I see the light, I honor your tears.”

Traumatic brain injury survivors use masks to tell story

Wednesday, July 6th 2016, 12:16 pm HST Thursday, July 7th 2016, 1:49 am HST

By: Susanna Black, Weekend Anchor/Reporter



Traumatic brain injury survivors are taking part in a mask-making program. (Source: WECT)

Two people in Wilmington with traumatic brain injuries are turning to a simple arts and crafts activity to help with their recovery process.

Unmasking Brain Injury is a program, created by Executive Director Marty Foil, that lets survivors create masks depicting their struggles and triumphs during their recovery.

He said it was inspired by an article in National Geographic that featured soldiers who had done masks as part of their therapeutic experience.

After showing the article to his staff, they took the first masks made by survivors to a fundraiser, where he says people were mesmerized.

“The brain injury field has never had a really powerful advocacy tool and really lags in awareness and we saw this as what could be potentially the perfect tool for someone with a brain injury to advocate for themselves to tell their story and explain to somebody else in a way they can understand what it’s like to live with a brain injury,” Foil said.

He said there are between nine and ten states doing the project under the Unmasking Brain Injury banner.

“This may be the one thing we’ve found that could be our AIDS quilt for brain injury,” Foil said.

Wendy Lewis's life changed when her traumatic brain injury accident happened all while making a sandwich.

“The next thing I knew I was in the light and when I came out of it I was lying flat on my back on the concrete for two days and no one found me,” Lewis stated.

Another local, Jason Burke, who also experienced a traumatic brain injury accident, recalled the time his happened in 2013.

"We were on a six-person golf cart," Burke said. "I was on the back, turned to talk to someone, we hit something in the road, it bounced me off, I landed on my feet and I flipped nine times."

Jason was in a coma for a month. "After rehab, it was very scary when I left this hospital," Burke said. "It was like I wanted to leave, but when I got home I was like 'oh, crap...how am I going to live life now?'"

Lewis and Burke said day-to-day life was tough, but with the help of arts and crafts supplies and an untouched mask, they saw a glimmer of hope.

"Making that mask, I didn't know I still had hope," Lewis said.

Lewis and Burke showed off their masks and explained the meaning behind each painting and bead.

"Even though all our masks tell a totally different story, it identifies you with each other because I can guarantee you somewhere along the way we've felt like that other person," Lewis said.

Burke said he hopes his mask will send a message to those going through their own journey to never give up.

"I hope it gives strength and hope that may be sitting in a dark room, thinking, 'I'm the only one', well, you're not," Burke said.